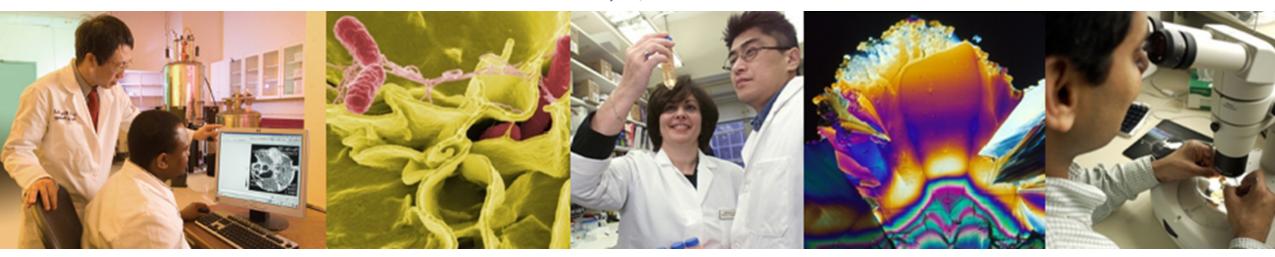
Report of the ACD Working Group Ad Hoc Virtual Meeting on AI/ML Electronic Medical Records for Research Purposes

Special Meeting of the Advisory Committee to the Director (ACD)

May 6, 2021







December 2019 – ACD Artificial Intelligence WG



Rediet Abebe Cornell



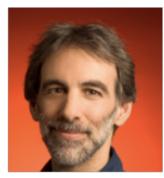
Greg Corrado, PhD Google



Kate Crawford, PhD Al Now Institute



Barbara Engelhardt, PhD Princeton



David Glazer Verily (Co-Chair)



David Haussler, PhD USCS



Dina Katabi, PhD MIT Computer Science & Al Lab



Daphne Koller, PhD insitro



Anshul Kundaje, PhD Stanford University



Eric Lander, PhD Broad Institute



Jennifer Listgarten, PhD Berkeley



Michael McManus, PhD Intel

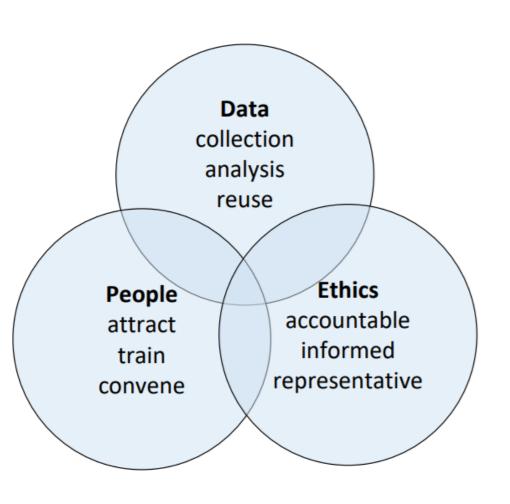


Lawrence Tabak, DDS, PhD NIH (Co-Chair)



Serena Yeung, PhD Harvard

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The opportunity is huge

 including to drive discontinuous change

We need new data generation projects

NOT business-as-usual

The single best way to attract the right people is with the right data

"Show me the data"

The time to invest in ethics is now

Before we dig a deeper hole

ACD AI/ML Electronic Medical Records for Research

Purposes

EXTERNAL MEMBERS

Rediet Abebe, Ph.D.

Assistant Professor of Computer Science University of California, Berkeley

Atul Butte, M.D., Ph.D.

Professor, Pediatrics Priscilla Chan and Mark Zuckerberg Distinguished **Professor** University of California, San Francisco

Kate Crawford, Ph.D.

Labs – New York City Visiting Chair of AI and Justice at the École Normale Supérieure Miegunyah Distinguished Visiting Fellow at the University of Melbourne

Joel Dudley, Ph.D.

Chief Scientific Officer Tempus Labs, Inc.

Barbara Engelhardt, Ph.D.

Associate Professor, Department of **Computer Science Princeton University**

David Glazer

Engineering Verily

Jianying Hu, Ph.D.

IBM Fellow; Global Science Leader Al for Healthcare Senior Principal Researcher at Microsoft Research Director, Center for Computational Health

Dina Katabi, Ph.D.

Andrew and Erna Viterbi Professor MacArthur Fellow Massachusetts Institute of Technology

Abel Kho, M.D.

Director, Institute for Public Health and Medicine Northwestern University

Ryan Luginbuhl, M.D.

Principal, Life Sciences Division MITRE Corporation

Brad Malin, Ph.D.

Accenture Professor Biomedical Informatics, Biostatistics, and Computer Science Vanderbilt University

Jimeng Sun, M.Phil., Ph.D.

Health Innovation Professor Computer Science Department and Carle's Illinois College of Medicine University of Illinois Urbana-Champaign

Serena Yeung, Ph.D.

Assistant Professor, Biomedical Data Science Assistant Professor, by courtesy, of Computer Science and of Electrical Engineering **Stanford University**

ACD AI/ML Electronic Medical Records for Research Purposes

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Director, National Library of Medicine

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Director, National Eye Institute

Joshua Denny, M.D., M.S.

Chief Executive Officer,

All of Us Research Program

Eric Dishman

Chief Innovation Officer, All of Us Research Program

Susan Gregurick, Ph.D.

Associate Director for Data Science

Helene Langevin, M.D.

Director, National Center for

Complementary

and Integrative Health

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Director, National Institute of General

Medical Sciences

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Director, Center for Information Technology

Chief Information Officer

Joni Rutter, Ph.D.

Deputy Director, National Center for Advancing

Translational Sciences

Tara Schwetz, Ph.D.

Associate Deputy Director

Norman Sharpless, M.D.

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Lawrence Tabak, D.D.S., Ph.D.

Principal Deputy Director

Carrie D. Wolinetz, Ph.D.

Acting Chief of Staff

Associate Director for Science Policy

Charge to the Working Group



- Identify unique research opportunities for NIH to apply resources in a practical way to make electronic health records (EHRs).
- Identify EHR research challenges that AI/
 ML could have the greatest impact.
- Determine barriers to the widespread use/ deployment of AI/ML capabilities can NIH support help overcome.
- Identify the partners that would be needed and incented to help scale these capabilities.

Impactful AI/ML Research Challenges

- Start by addressing the needs of marginalized communities. If these communities remain an afterthought, the same inequities will be repeated.
- Address the significant errors, gaps, and racial and gender inequities in EHR data.
- Using problematic data for models will amplify the gaps. The foundation that the models are being built on must be addressed
 - Example: 50,000 COVID-19 patients, more than half of whom are Black, however, rigorous methods to analyze these data do not exist, because of confounding factors such as disparate treatment by physicians.

Impactful AI/ML Research Challenges

- Community-enabled real-world effort to encourage solicitation of networks of clinics/systems
- Create consortia among all groups that participate to enrich data collection and sharing
- Create clinical trials networks for the rapid validation of algorithms
- Analyses of dense data (e.g. medical images) and to study diseases that do not translate well from models
- Design methods to impute or fill in missing data, social determinants of health and actual outcomes





Barriers to the Widespread Use/Deployment

- Information infrastructure that is needed includes not only EHRs but also the network of large-scale data repositories and imaging studies
- Clinical data capture is human intensive, biased, incomplete, and sparse
- EHRs provide only a partial picture of health and health care experience
- Inconsistent quality of the content, integrity of data, research usefulness of EHRs
- EHR accessibility is a serious problem

Addressing Barriers

- Create a body that could be the translator and take data and de-identify data, and then provide the data to the end users
- Create an infrastructure to facilitate designing and testing algorithms and comparing them across institutions
- Invest in earlier-stage research that private industry is reluctant to fund
- Clarity is needed on ownership and sharing of the ML produced after public shared data are used

Strategic Partnerships

- Who are the partners that would be needed and incented to help scale these capabilities
 - Al Industries, Computing Partners, Academic, Research, and Nontraditional Partners
- NIH investment needs to add meaningful complements to what is already being done by the community
- Focus on sustainable infrastructure through strategic public/ private partnerships







Compelling Ideas Emerge

 Support for AI/ML work to redress the challenges of health disparities, health inequality, and minority health

> Develop the infrastructure and training of diverse researchers

Catalyzing access to high quality diverse data sets

 Address the errors and biases in EHR data and linking EHR with Social Determinants of Health

Improve the...

Quality of the content in EHRs

- Innovative ways to use AI strategies (robotics, computer vision) when capturing the patient experience
- Computational approaches to debiasing data to avoid perpetuating biased understanding of health and the patient experience

Integrity of data in EHRs

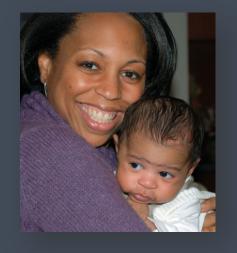
- Advance the use of standards in the capture of clinical data
- Deploy AI methods to support computational coding at scale

Research usefulness of EHRs

- Identify high priority problems worthy of solutions
- Model validity and verification
- Security, equity, and privacy

Tools for clinical care

- Integrative data models that enrich understanding of health beyond the data available in the EHR
- Methodology that supports translation and transparency
- Ensure that models are fit for purpose









Lawrence.Tabak@nih.gov

NIH...

Turning Discovery Into Health



